WHAT IS HOSPICE?

Introduction. In planning for one's own or a loved one's end of life care, it is important that Friends' conversations with family and physicians occur early, if possible, well before a health crisis is encountered. It is equally important that these conversations include information about all of the available care options. One important option Friends might consider is ***hospice***.

Even though the so-called "modern hospice movement" has been active in the U.S. since the 1970s, the nature of hospice care may still be unfamiliar and is often misunderstood. Some Friends may recall the specter of "death panels" that was raised during the legislative efforts to pass the Affordable Care Act, or they may associate hospice with "giving up," only to be used as a last resort. Possibly as a result, many patients and families have expressed that they wished they had begun hospice care earlier than was done, according to many sources. Some studies have also shown that hospice patient may actually live longer under hospice care than without.

The information that follows is provided as a general introduction to the nature of hospice care and related subjects, such as insurance coverage and how to find and choose a hospice. This information is intended as a summary and is by no means exhaustive; links are provided to web sites of hospice related organizations for additional information that may prove helpful. Some specific references are made to some hospice organizations in the Greater Washington, DC area, but are not intended to recommend any specific hospice(s) over another.

What is hospice? Hospice is a form of palliative care, which is that branch of medicine focused on providing relief from the symptoms and stress of serious illness. The goal of palliative care is to relieve pain and suffering and provide the best possible quality of life for patients and their families. It can be provided at any stage of the illness or condition.

Hospice, sometimes called "comfort care," is palliative care specifically for persons with life-limiting conditions and is usually provided in the last months, weeks and days of a patient's life. Hospice focuses on managing pain and keeping a patient comfortable so that he or she can enjoy a good quality of life for the remainder of their time, neither hastening nor postponing death, but rather allowing a natural death while promoting dignity and relieving suffering.

A brief history of the so-called "modern hospice movement" in the U.S. can be found at the California Hospice and Palliative Care Association website.

Where hospice care is provided. Hospice can be provided anywhere: at home, a nursing home, an assisted living facility, or a hospital. Most hospice care is provided in patients' homes, where the vast majority of people prefer to spend their final days. Hospices bring everything you might need to the home — medications, hospital bed, bedside toilet, medical staff, expert consultants — tailored to your needs.

If "home" is in a retirement or nursing facility, hospice can come to the facility and will coordinate with the facility staff in providing care for the patient. Many long-term care facilities and some hospitals have hospice units where hospice care can be provided.

Some hospices also have their own inpatient facilities that can be used to provide care on a temporary basis when care in the home is not practical, such as when more acute care is needed, or to provide respite for caregivers. Montgomery Hospice's Casey House is an example of such a temporary inpatient facility.

Must All Medications Be Given Up When One Enters Hospice? No. While hospice focuses on a relief-based and not curative-based approach to care, the decision to halt medication while in hospice care is usually left up to the patient (or family, if the patient does not have capacity) on a case by case basis. Medications that provide for alleviation of symptoms are typically allowed. Even some treatments that might be considered curative may be continued if their primary purpose is alleviation of pain or discomfort; for example, in some situations forms of radiation and chemotherapy for cancer patients may fall within this category.

Eligibility and payment for hospice. Generally, hospice care is available to anyone of any age living with an end-stage medical condition. The more pertinent question is usually who will pay for hospice care.

Medicare, Medicaid (in most states), ***VHA***, and ***most private insurance plans*** provide for hospice benefits and have eligibility requirements in order to receive these benefits. Below is a general summary of the eligibility requirements under most insurance plans:

Medicare and most private insurance require that the patient must:

- be 65 years or older;
- be diagnosed with a terminal illness;
- have the patient's doctor and a hospice medical director certify that the patient has *six months or less to live* if their medical condition follows its normal course; and
- agree to forego *curative* treatment for their underlying terminal condition.

Medicaid programs in most states follow eligibility guidelines similar to Medicare, except for the age requirement and except that patients under age 21 do not have to discontinue curative treatment. (See also: https://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html)

Note: When hospice care is provided at long-term care facilities, room and board costs are typically not covered by Medicare or Medicaid.

In cases of financial hardship many hospices can provide services at reduced or no cost for persons who are not eligible for benefits and cannot afford payment. These reduced charges are often provided by charitable foundations associated with a hospice provider.

How Long Do Hospice Benefits Last? Under Medicare and most private insurance plans, the length of time the hospice benefit is available is flexible. Initially, hospice medical director and patient's personal physician (if applicable) certifies that the patient has a life expectancy of six months or less if the illness runs its normal course; thus, the first two certifications are for 90 days each. Thereafter, the physician(s) may re-certify eligibility every 60 days so long as the patient's life expectancy remains six months or less if the illness runs its normal course.

Admission to Hospice. Individuals are usually referred to hospice by their personal physician, although individuals can be referred by their families or even by themselves. Hospice usually begins within 48 hours after a referral, and can begin sooner based on the circumstances. The hospice admissions person, usually a nurse, evaluates what the person and family need and develops a plan of care.

What Services Are Included. The care plan addresses the entire family's needs: medical, emotional, psychological, spiritual and support services.

Medicare defines **four distinct levels of hospice care** which every Medicare-certified hospice must provide:

- routine home care
- continuous home care,
- general inpatient care, and
- respite care.

Further detail about the kinds of services provided under each level of care can be found at verywellhealth.com.

In addition to these four levels of care, hospices typically provide:

- **Bereavement counseling** and support to the family for up to 13 months (or longer, if needed) after the death of their loved one.
- **All medications** related to the terminal diagnosis.
- **Medical supplies and appliances** related to the terminal illness.
- **Patient and family education** (i.e., teaching family caregivers how to provide care).
- **Short-term inpatient care**, including respite care.
- **Other services as required**, including physical, occupational, dietary and speech-language therapy.

Who Provides the Care in Hospice? Hospice services are provided by an ***interdisciplinary team*** ("IDT") comprised of many different kinds of professionals who provide medical care and support services. The typical hospice IDT includes the following:

Physician*
Nurse (and/or Nurse Practitioner)
Certified/Geriatric Nursing Assistants
Social Worker
Chaplain
Trained Volunteers
**A patient's personal physician may also be a part of the hospice team and may continue to bill for professional services; those services are typically not covered by hospice.*

Many hospices offer additional services, including psychologists; psychiatrists; music, art, or pet therapists; nutritionists; and occupational, speech, massage and physical therapists. **Trained volunteers** are often employed as part of the IDT and may provide a range of services including companionship: respite for caregivers; running errands; simple housekeeping, etc.

With all of these services, the person receiving care still remains in charge of his or her medical decisions.

Lastly, most hospices also have **bereavement counsellors** who provide support for the family and loved ones after the patient dies, usually for up to 13 months after death.

Are All Hospice Providers Alike? Hospices are not all alike. In addition to differences in the size of the organization, following are some of the differences of which one might want to be aware:

1. **Not-for-Profit vs. For-Profit.**
   Originally hospices were mostly charitable not-for-profit agencies. However, in recent years there has been a significant increase in the number of for-profit hospices, created to take advantage of the profit potential in the Medicare Benefit as well as our aging population. For-profit hospices made up 30% of the 2,255 hospices in 2000; by 2016, that proportion jumped to two-thirds of the nearly 4,400 hospices in operation.

   Not-for-profit hospices exist to serve patients and their community. Financially their objective is to break-even, with any excess of income over expenses being reinvested to serve their patients. They are typically classified as charitable organizations by the IRS and are exempt from paying income taxes.

   For-profit hospices exist not only to serve patients and their community but also to make profits for their owners. Any profits they realize on their revenues are taxable, adding another layer of expense to their normal operating costs. Otherwise, for-profit hospices operate similarly to not-for-profit hospices. Currently the largest hospice providers in the U.S. are for-profit.

2. **Medical vs. Non-medical.**
   A small percentage of hospices are classified as "non-medical." Non-medical hospices are typically not-for-profit, mainly volunteer organizations which provide companionship and emotional support, perform errands, household chores, and meal preparation, and provide transportation, respite for caregivers, bereavement, and other services for persons with terminal illness. Medical services are not included. Typically, these agencies do not charge for services. They are not eligible for the Medicare hospice benefit and usually raise funds from donations to fund their operations. They also have more flexibility in when they can admit patients to their care (i.e., not bound by Medicare's 6-month rule). A local example of a non-medical hospice is Hospice Caring in Gaithersburg.

Are All Hospices Non-Sectarian? Under applicable ethical guidelines, hospices are required to respect the individual religious preferences of patients and families. Thus, chaplains who are part of the inter-disciplinary team in a Medicare-approved hospice are trained to provide spiritual care to persons of any faith tradition, or no faith tradition. In all cases spiritual care is always optional for the patient and family.

Some hospices are nominally affiliated with a particular faith tradition, e.g., a "Christian" or "Jewish" hospice (e.g., Jewish Social Services Agency or JSSA Hospice in Montgomery County). While these hospices, if they are Medicare-approved, must be non-sectarian with regard to admitting and serving patients, the chaplains employed at such hospices are often from the nominal faith tradition, and the values and practices of that faith tradition typically guide the policies and practices employed by the agency.

What Questions Should I Ask When Choosing a Hospice? Below is a suggested list of questions you should consider when looking for a hospice program.

- What services are provided?
- What kind of support is available to the family/caregiver?
- What roles do the attending physician and hospice play?

- What do the hospice volunteers do?
- How does hospice work to keep the patient comfortable?
- How are services provided after hours?
- How and where does hospice provide short-term inpatient care?
- With which nursing homes or long-term care facilities does the hospice work?
- How long does it typically take the hospice to enroll someone once the request for services is made?

Another very helpful list of questions can be found at the americanhospice.org website.

For further information about hospice care, see:

- https://hospicefoundation.org/
- https://www.aginginplace.org/hospice-care/
- https://americanhospice.org/learning-about-hospice/

How to find a hospice.

- For a listing of available hospices in ***Montgomery County***, see: https://www.montgomerycountymd.gov/HHS-Program/Resources/Files/A&D%20Docs/DND/DNDHospiceServices.pdf
- For a listing of available hospices in ***Washington, DC***, see: http://www.nationalhospicelocator.com/hospices/district-of-columbia
- **For all other locations,** and to find information **to compare hospices**, including consumer assessments of different providers, **Medicare** provides a useful search tool at: https://www.medicare.gov/care-compare/?providerType=Hospice&redirect=true#search